SAHLGRENSKA AKADEMIN
INSTITUTIONEN FÖR VÅRDVETENSKAP OCH HÄLSA

YOUNGER PATIENTS' EXPERIENCE OF LIVING WITH MECHANICAL CIRCULATORY SUPPORT

A phenomenological-hermeneutic study

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Uppsats/Examensarbete:	15 hp
Kurs:	Master OM5150
Nivå:	Avancerad nivå
Termin/år:	Vt 2018
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Conflict of interest statement

None to declare

Abstract

Aims and objectives: To describe younger patients' experiences of living with a mechanical circulatory support with focus on self-efficacy.

Background: Heart failure is increasing even among younger patients. Life-threatening heart failure can occur and the patient will need heart transplantation. Treatment with mechanical circulatory support (MCS) may be necessary. Living with MCS in the form of a biventricular assist device (BiVAD) means living with a visible mechanical device attached to the body. There are no qualitative studies published describing only younger patients' experiences of living with BiVAD, and how it affects their perception of their bodies. Self-efficacy plays a decisive role in dealing with threatening situations. It is important to gain in-depth knowledge of what BiVAD treatment means and how self-efficacy affects the patient's ability to handle this life change.

Design: A qualitative interview study with eight adults participants.

Methods: The data was analyzed using the phenomenological-hermeneutic method.

Results: An overall theme, *Navigating from helplessness to feeling strong in the new reality*, and three themes emerged: *Feeling homeless in a changed reality* describes the experience of suddenly falling ill and the loneliness caused by the disease. *Finding my own inner resources* shows that the interviewees found the strength to fight for their lives and began to regain control of their situation. *Adapting to my new reality* describes the importance of drawing strength from others and being able to see MCS as a friend providing respite from the disease.

Conclusions: Self-efficacy belief plays a significant role for younger patients to be able to accept MCS treatment and to handle a changed reality.

Relevance to clinical practice: When patients treated with MCS experience control over their situation, they can be transferred to a cardiology outpatient clinic, which for the patients imply a step towards independence and a sense of normality.

Key words

heart failure, mechanical circulatory support, patient's experience, phenomenological-hermeneutical, self-efficacy, the lived body

Introduction

The incidence of heart failure is increasing, even among younger patients in age group 18-44 years (Barasa et al., 2014). In some cases, the disease develops and becomes so serious that the patient becomes a candidate for heart transplantation, which is currently the most effective treatment of severe heart failure. As the availability of organs is limited, the waiting period for a transplant can be long. Life-threatening heart failure may develop and the patient may need mechanical circulatory support (MCS) in the form of a mechanical heart pump to survive until heart transplantation (Ozbaran et al., 2013). Sudden onset of a life-threatening disease requiring a heart transplant is a traumatic experience (Zipfel et al., 1998).

Merleau-Ponty describes the body in a philosophical perspective, as not just living but lived. It is the lived body that is our home in the world. In the case of illness, we cannot leave our bodies behind us, as the body is always with us. This body is both foreign and familiar to us when we are sick (Merleau-Ponty, 2012; Svenaeus, 2011). To be treated with MCS in the form of a heart pump system that support both left and right ventricles (a biventricular assist device, or BiVAD) means living with a conspicuous mechanical device attached to the body. The battery station, controller and pump chambers are outside the body (Ozbaran et al., 2013) and cannot be concealed, so are visible as an ever-present attachment to the patient.

Background

A strong indication for MCS treatment is present in congestive heart failure when the patient is judged to be in function class IV according to the New York Heart Association Standardized Classification (NYHA). In spite of optimal drug treatment, these patients are expected to have a poor prognosis for the progression of the disease, with a one-year mortality rate of approximately 50% (Lund, Matthews & Aaronson, 2010). Patients treated with MCS as a bridge to transplant survive to a greater extent, and the risk of dying is reduced by 48% compared to those receiving optimal drug treatment (Rose et al., 2001). However, for young people to suffer from such severe heart failure is unusual. In the Swedish Heart Failure Registry from 2000 to 2013, were 2247 patients reported in the age group under 65 years, and only 8% were judged to be in NYHA function class IV (Thorvaldsen et al., 2014). The German Heart Institute in Berlin implanted 1456 MCS devices in the years 1988–2010, and 37% of the patients were 13–50 years of age (Potapov et al., 2012).

Different pump systems have been developed in recent years. The technology has improved and today the systems used mainly have a continuous-flow mechanism, which has improved treatment results, and the number of implants has increased. In German registry data, a 180% increase in MCS implants over the last 10 years has been reported (Beckmann et al., 2016). The American INTERMACS database (Interagency Registry for Mechanically Assisted Circulatory Support) contains 15745 patients registered between 2006 and 2014. Of these, 4.4% were treated with BiVAD. Severe biventricular heart failure is a very serious condition and these patients had a significantly worse one-year survival rate compared to those treated with a left ventricular assist device or LVAD (55% vs. 80%) (Kirklin et al., 2015). Sahlgrenska University Hospital on the other hand, has shown a similar survival rate between the BiVAD and LVAD groups (86% vs 90 %). The BiVAD population was younger and more patients were women (Bartfay et al., 2017). Both 30-day and one-year survival deteriorated if implantation occurred in critical cardiogenic shock (Potapov et al., 2010).

Previously, qualitative studies on MCS treatment have had a mixed-age patient population. This research describes how patients during MCS were struggling to adapt on various levels to their new life situation (Casida, Marcuccilli, Peters & Wright, 2011; Chapman, Parameshwar, Jenkins, Large & Tsui, 2007; Savage & Canody, 1999) and to their changed self-image and body image (Chapman et al., 2007; Hallas, Banner & Wray, 2009; Marcuccilli, Casida & Peters, 2013). Managing daily activities was important, giving a sense of normality and control (Hallas et al., 2009; Marcuccilli et al., 2013). Elderly patients found it easier to adapt to the limitations resulting from MCS treatment than younger patients did. Younger patients, however, found it easier than older patients to learn how to handle the heart pump (Overgaard, Grufstedt Kjeldgaard & Egerod, 2012), and the MCS was accepted to a different extent (Modica et al., 2015; Sandau, Hoglund, Weaver, Boisjolie & Feldman, 2014). Sandau and co-workers (2014) defined a good quality of life during MCS treatment as being well enough to perform and enjoy everyday activities that were significant to the individual patient (Sandau et al., 2014). Improved self-management in MCS treatment can increase the patient's quality of life. Factors in self-management that can significantly predict an increased quality of life, are high cognitive ability ($p = 0.002$) and compliance with MCS guidelines ($p = 0.006$). Factors were measured with a generic QOL instrument, (Casida, Wu, Abshire, Ghosh, & Yang, 2017).

Human self-efficacy plays a decisive role in dealing with stress and threatening situations. A deep inability to cope with various life events or exercise control over troublesome, persistent situations is the greatest obstacle to being able to adapt to an emerging situation in a good way (Benight & Bandura, 2004). There are no qualitative studies published describing only younger patients' experiences of living with MCS in the form of BiVAD, focusing on self-efficacy and how BiVAD affects the patient's body perception. With in-depth knowledge, the multidisciplinary health-care team can understand and support the patients in a better way, motivating this qualitative study.

Aims and Objectives

To describe younger patients' experience of living with mechanical circulatory support, focusing on self-efficacy.

Methods

Design

A qualitative interview study was conducted in order to be able to capture the patients' reactions to and experiences of living with mechanical circulatory support and specifically a BiVAD. By examining the significance of phenomena in the lived experience of the interviewee, the essence and meaning of these phenomena can be captured and understood. The phenomenological-hermeneutical method involves understanding and explaining the phenomena by carefully examining and interpreting the stories of the interviewees (Lindseth & Norberg, 2004). An interview guide with four open questions covering the purpose of the study was designed.

Settings and patient selection

Sahlgrenska University Hospital is the only centre in Sweden to treat severe biventricular heart failure with BiVAD in form of a para corporeal pump and with blood chambers outside the body. So study

participants could only be recruited from this centre. Preliminary information about the study was given as soon as the patient was treated with MCS. The MCS treatment had to be completed and heart transplantation carried out before inclusion in the study was possible. The eligible patients were contacted by phone at least one month after the heart transplant with a request for participation. A maximum of one year had to have elapsed since the heart transplant. Written information about the study was then sent to the patient. A consecutive selection was made, allowing all patients between the ages of 18 and 44, and who met the inclusion criteria between November 2013 and February 2017 to be included. The age range 18-44 years, was chosen according to the increasing incidence of heart failure in these ages (Barasa et al., 2014). Criteria for exclusion was not being able to answer interview questions in Swedish or English.

Data Collection

Eight interviews were conducted, one in English, at Sahlgrenska University Hospital between November 2013 and February 2017. The participants had been offered the option of being interviewed at home, but all chose to be interviewed at the hospital. The heart transplant had occurred 1–12 months earlier. The interviews lasted between 30 minutes and two hours and gave a very rich material. Both authors (ML, KH) was present at each interview, except at one interview. One had the main responsibility for the interview and the other acted as an assistant with the opportunity to ask supplementary questions at the end of the interview. The main responsibility varied. The interviews were digitally recorded, and notes were taken during the interviews.

Data analysis

The authors listened to the recordings and the interviews were then transcribed verbatim. The transcriptions were read several times to capture the whole meaning. This initial understanding of the text was formulated in a *naïve reading*. In the subsequent structured analysis 396 meaningful units were identified in the text, which were reflected against the naïve understanding. These meaningful units where condensed by highlighting the essence of the statement. Similarities and inequalities were identified and sorted into subthemes that were then collected under themes. Then a main theme could be identified. Main theme and themes were compared with the naïve reading and validated it. Finally, the results were critically considered in relation to the literature. (Lindseth & Norberg, 2004).

Ethical considerations

In the design of the study, any risks to the interviewees were weighed against the benefit of highlighting new knowledge, and the benefits considered the risks. The study design fulfils the Declaration of Helsinki on ethical principles for medical research involving human subjects (World Medical Association, 2013). The research plan was approved by the Regional Ethical Review Board of Western Sweden (approval number DKr 458-14). Written consent for participation was obtained from the interviewees after both oral and written information about the study was given, as well as guarantees of confidentiality when publishing the study results. Interviewees were given the opportunity to ask questions after the interview. Provision was made for contact with a psychologist, which was used once.

Results

Naïve understanding and reading

Being treated with mechanical circulatory support meant that the normal life had come to a standstill and the new life situation had limitations. The patients experienced a fear of losing their lives and they had a sense of loneliness and alienation. Their own body felt weak, lacerated and foreign. In order to endure in the new reality, it was important that the life with mechanical circulatory support was temporary. The life with mechanical circulatory support can be seen as a journey towards a goal, where the goal was to get rid of the pump by a heart transplant. To accept their new reality, patients could find strength to struggle, to advance on the journey. The patients experienced a solidarity to each other when they met to exchange experiences. They felt strengthened and hopeful that there was a future for them.

Findings

Eight patients were recruited consecutively, without loss, to the study: six women and two men, mean age 28 years. The average duration of MCS was 138 days. (Table 1). The patients had very serious biventricular heart failure with the diagnoses dilated cardiomyopathy, (DCMP), postpartum DCMP or postpartum myocarditis. Their ejection fraction was between <10% and 20%. Seven of the interviewees had fallen acutely ill with a life-threatening condition. They had been treated under anaesthetic without the possibility of being involved in the decision on treatment with BiVAD.

The data analysis resulted in an overall theme, three themes and 16 subthemes (Table 2). The overall theme, *Navigating from helplessness to feeling strong in a new reality* describes the process that the interviewees went through in their changed reality, while they were treated with MCS (Figure 1). The first theme, *Feeling homeless in a changed reality*, describes the interviewees' experiences of falling acutely ill with a life-threatening disease and how the disease affected all aspects of their lives. The second theme, *Finding my own inner resources*, shows how the interviewees began to accept their situation and found power and determination to bear their situation while they were treated with MCS. Finally, the third theme, *Coming to terms with my new reality* describes external factors, such as the importance of being strengthened by their surroundings, that help them to adapt to their situation. The patients are referred to in the quotes below as P1 to P8.

Theme 1: Feeling homeless in a changed reality

The first theme and its subthemes describe the interviewees' experiences of sudden onset of the disease. They experienced a range of emotions that needed to be processed. They had lost their empowerment because they were dependent on others. They experienced their own body as strange and invaded. It had let them down and they mourned their sick heart. The interviewees felt lonely and different. Life was going on around them, but their own life was at slow speed.

A sudden change in life

The interviewees described their shock on waking up to discover that they had a life-threatening illness. It was frightening and they felt both anger and a sense of meaninglessness about their situation: "When I woke up, I didn't understand at first that it was true, because I thought I was

perfectly well and my heart was great" (P3). Seven out of eight had started the MCS treatment with a BiVAD during the intensive care period without being able to participate in the decision to insert the heart pump: "They had already implanted the heart pump when I woke up" (P2). They felt a sense of unreality and some interviewees felt like they were in a nightmare when they found the heart pump attached to their body: "I panicked of course, because I didn't know if it was for real, so I tried to pull everything off me" (P4).

Lost empowerment

The interviewees were dependent on others and on MCS for their survival. They experienced a real threat of dying and they were aware of the fragility of life. They were only alive thanks to the MCS treatment. The interviewees had to surrender to the medical staff, there was no room for their own choices or influence: "You felt very locked in ... You were hooked up to a machine that kept you alive" (P4). They felt powerlessness: "It also makes you panic when you don't have any control and you can't move, all power lies in everyone else's hands" (P3).

An invaded body

The interviewees experienced their own body as alarmingly different when they woke up after a long period of intensive care: "I was really upset every time I looked in the mirror so I put it off as much as I could" (P7). Some interviewees were disgusted by their body and were ashamed of their changed appearance: "I think it was quite disgusting to have such a thing. It's these tubes that make it look so brutal I think. It's just not me. I don't want to be associated with it" (P3). Some interviewees experienced panic attacks over the tubes that connected the pump to their body. They were constantly aware of the presence of the pump because it had invaded their body.

Being let down by my weak body

The interviewees were aware that it was not their real heart keeping them alive; they were dependent on an artificial heart to survive. They felt let down by their own weak body: "Why shouldn't I have the same right to live as everybody else ... why am I less worthy than others because I got sick, because my heart wasn't strong enough to help me?" (P4). One interviewee expressed guilt feelings for being alive, while another felt humiliated by her body's failures. They mourned their sick heart: "It still grieves me that my heart doesn't work" (P3). Some of the interviewees expressed ambivalence about needing a heart transplant: "I didn't want to have this, I just wanted it to be whole again but that's not the way it turned out" (P8).

The loneliness of the disease

Living with MCS and specifically BiVAD meant a feeling of being alone and looking different: "All the while I went around with the pump I felt, you know, this isn't me ... I didn't want people to accept me like that because it wasn't me. That wasn't how I wanted to live" (P4). The pump could not be concealed, which put a great strain on the interviewees when they went about their business in the community. The constant noise from the pump also attracted unwanted attention: "You don't want to go out with it because everyone asks, what is that, what, what? Then I think no, I'll just lock myself away" (P1). "You get very many reactions that you have to deal with because some people think it's disgusting" (P3). The loneliness of the illness became especially evident in the youngest interviewee, who expressed the difficulty of handling a crisis at such a young age.

Life in the slow lane

Life during MCS treatment meant restrictions and limitations in daily life. The interviewees could

adapt to some situations whereas others had to be completely excluded. For example, those who were parents could not take care of or be close to their children. Life was always lived according to the limitations imposed by the pump treatment. The pump was a hindrance and they were physically connected to it, shackled in their own body: "I was stuck whith so much, of course" (P8). They did not dare to plan for the future: "You don't dare to plan, planning is hard" (P5). One patient expressed it as standing at the side of his own life: "You see and are there when everyone else is doing things, [you see] how the world continues to be, but you are not there taking part in it. You are sitting there like a spectator on the substitutes' bench" (P4).

Theme 2: Finding my own inner resources

The second theme describes how the interviewees, after processing their feelings, began to accept their situation by facing the disease. They dared to surrender to the nurses and, by focusing on other things than the MCS treatment, they found their inner strength to endure their situation and fight to live. Being self-confident was important, as well as experiencing a sense of regaining control over the situation.

Facing the disease

Knowing that the MCS treatment was vital meant that the interviewees could meet their illness and accept their changed reality: It's better to have some limits than to be unable to do anything because you aren't alive" (P7). This also meant that they could see the MCS treatment in a more positive light: "I'd have been dead otherwise, that's a fact, I had a positive feeling about the pump" (P8). Because the interviewees had begun to accept their changed reality, it also meant that they accepted the fact that they had become so seriously ill. Then their grief over their own weak body could diminish: "I didn't feel my life was worth living but in time I understood that it definitely is" (P4).

Daring to surrender

As time went by, the interviewees developed a more pragmatic attitude to their life situation. They felt trusting and secure in the knowledge that the medical team had control of the situation: "I just go along with them, they know what they're doing and I'm certainly not afraid" (P4). "When I went for the heart transplant, it was like, yes but if I die here on the operating table, I can't think of any better way than that" (P5). They dared to surrender themselves and let go: "You were confident that the medical team knew what they were doing, you know, that you could put your life in their hands" (P2). They realized that by daring to surrender, their wellbeing could increase.

Managing to endure it

The period of MCS treatment meant that they could tolerate their situation. In order to endure this period, the interviewees focused on other things than the pump itself, trying to keep themselves occupied: "You kind of divide the day up, there's a new medicine ... there's something good on TV ... physiotherapy and visits" (P8). Knowing that the MCS treatment was temporary and that they would at some point get a heart transplant was important: "It's temporary, it can happen at any time, no one knows" (P6), as was living in the here and now given their uncertain future:" "I felt things were pretty fragile, so I tried to also live for the moment and try to live as well as possible with the pump" (P3). It was also important not to get bogged down but focus on one thing at a time and think positively. In this way they could bolster their own ability to handle their life situation.

Finding my inner strength

The interviewees described how they eventually decided to fight to survive. They felt determined, not

least for those who were a parent and must exist for their children: “It took a while before I felt I really wanted to fight and get through this, you know, it took a few days for me to feel that way” (P2). Becoming as strong as possible before the heart transplantation was important: “The only thing that made me fight was that I want to still be around and to be as strong as possible for the transplant” (P3): They found an inner strength and they decided that they could survive: “The doctor comes in and says, your heart is fragile, you only have 10% capacity and we don’t know how it will go. Then you feel like okay it’s so ... then I’ll do the last thing I can” (P4).

Feeling confident

The interviewees could gradually feel hope and confidence for the future. They felt confident that a new heart would come, especially when they were registered as a candidate on the transplant waiting list: “This is not about the rest of my life ... my heart will come soon” (P6). They could see that a normal life was waiting for them after the heart transplant. However, one interviewee hoped that his own heart would recover: “I still hoped I wouldn’t have to have a transplant, I hoped that for ages” (P8). Feeling that they could see progress was important, as well as being able to trust in their own ability: “This is going to work out, it will be alright. And that was what made me strong then” (P1).

Regaining control over my own situation

Getting control over certain parts of everyday life was important to the interviewees. In this way they could feel that they had influence over their daily lives, which strengthened their confidence in their own ability: “What I felt and what I could decide was how much exercise I had and how much I tried to get up and suchlike” (P2). It was significant when their physical strength improved: “I never thought I would walk again ... so it was awesome to get that strength back” (P4). Setting realistic goals gave an important sense of regaining control of their situation: “You do a job, set a goal, I will get there because I want to, because I knew it was good for me to think in that way” (P5).

Theme 3: Coming to terms with my new reality

The last theme describes a practical adaptation to the changed life situation. In order to reduce the loneliness of the disease and to come to terms with the new reality, it was important to the interviewees to be strengthened and supported by those around them. It was also important to trust the pump and see it as a friend. Then the interviewees could relax and live an ordinary life in which they could get respite from the disease.

Adjusting to a changed life

After facing the disease and beginning to accept the changed reality, it became possible to adapt to a changed life. The interviewees got used to the pump and learned to manage it in their everyday lives: “Then after a while when you got into it, there was no problem then, though it was still hard, but you could manage it” (P1). The interviewees adapted to the limitations that MCS imposed on their everyday life: “... .. Keeping as healthy as possible, so I didn’t dare live that way and go out and meet people, I’d rather hide myself away and wait. But that didn’t work either, so I had to live there and now” (P5).

Being strengthened by others

To be strengthened by their close friends and relatives, the nurses and their fellow patients was very important to the interviewees in order to feel at home in the new reality: “Then I met some others who were transplanted and then I felt, okay there is something better to come” (P3). Being genuinely listened to and understood as a unique individual also meant that the interviewees felt stronger: “Only

a millimetre outside my forehead, my reality didn't exist" (P4). Family support was invaluable. They felt affirmed when the nurses listened to them. In order to feel this support, it was very important that they were truly present and empathic: "To listen, like, when you, if you have something to say, that they really take the time to listen" (P2).

Seeing the pump as a friend

The interviewees reported that feeling that they trusted the pump and seeing it as a friend helped them to relax: "But then I tried to feel safe, that I'm safer now than before the cardiac arrest, because then I was like a ticking bomb. It works, it sounds good and it will make an alarm sound if it isn't working ..." (P3). They had come to terms with the pump. Some interviewees experienced some sort of normalization of their life situation: "I forgot it sometimes. There were times when I like, oh yes, I'll have the pump with me as well, so it became like a part of me, that you even forgot all about it" (P5). By feeling trust and confidence in the pump, they felt more at home in their new reality.

Respite from the disease

Humour made it possible to find respite from the disease by joking and chatting with the family or the nurses, as well as being able to perform and enjoy everyday activities: "I was in the computer, in my own world ... I was just hanging around with friends or took a drive, played video games" (P7). The interviewees were anxious to know that there was a regular life, which could mean friends coming to dinner or looking their best. Having their own place and having a room to themselves was significant. By forgetting for a while the MCS treatment they felt a sense of normality and freedom: "I came up with a trick. It was to wear earphones and headphones, then I could disappear for a few minutes" (P4). "When you sleep, you're free ... but as soon as you wake up ... then I heard it, of course" (P8).

Comprehensive understanding and discussion

The purpose of the study was to describe younger patients' experience of living with BiVAD, to gain in-depth knowledge of what treatment means, and to illustrate how self-efficacy affects patients' ability to handle their changing life situation.

The theme, *Feeling homeless in a changed reality*, describes how the interviewees suddenly found themselves in a changed reality when they had abruptly developed a life-threatening condition. Their own body, which had let them down was frighteningly unfamiliar. This corresponds well with Merleau-Ponty's philosophical description of the body as our access to the world, which means that in case of illness the world changes. Everyday life in the life-world changes as the body changes (Merleau-Ponty, 2012). Merleau-Ponty postulated that a changed body image is a traumatic experience that can cause a suppression mechanism when the lived body exists in two interpretations, the original and the present one. Because the body is different, the sick individual cannot connect to a changed life-world. The lived body, that is, the situation that has arisen, is not accepted (Merleau-Ponty, 2012). This reasoning is confirmed by the fact that the interviewees experienced their own body as disgusting and invaded, and felt that they did not want to be associated with the heart pump. They felt stared-at and strange. As Merleau-Ponty (2012) describes their being in the world was changed such that the fusion of body and soul was altered. The unique personal life-world had ceased to exist. In order to survive, an impersonal, marginal existence arose.

That the interviewees' unique personal life-world ceased to exist is consistent with losing empowerment and experiencing the loneliness of the disease. Life was going on around them, but their lives were severely restricted. The disease had interrupted their everyday life and they experienced a homelessness, in that their belonging in the world ceased. The loneliness of the anxiety induced by the severe disease took over, which Svenaeus (2011) has also described.

The second theme, *Finding my own inner resources*, describes how the interviewees, by processing what had happened, could gradually begin to accept their changed reality. They faced the disease and dared to surrender themselves to their treatment by having a more pragmatic attitude to their reality. This finding is supported by Merleau-Ponty's (2012) reasoning that describes how the person's own lived body must connect to and accept the actions that are taking place around it. Then the person can regain a sense of personal existence. By interpreting the new experiences that the changed body undergoes, the person can perceive the emerging situation as manageable.

By finding their inner strength and feeling resolute in this difficult situation, the interviewees could regain a sense of control. They felt confident they would cope with the situation and they felt hope. Self-efficacy increased when they could see their progress, and they managed to get through the time on MCS. Benight and Bandura (2004) describe the importance of self-efficacy as it has a protective effect. Self-efficacy implies the ability to exercise and maintain control in response to a traumatic event. Threats that arise are dangerous to those who doubt they can cope with a situation. When the feeling of being able to control their changed life situation increased, the interviewees experienced the situation as less threatening. By focusing on other things, living in the present and relying on their own ability, they could handle the situation, demonstrating the importance of good self-efficacy in managing life with MCS.

Finally, the third theme, *Coming to terms with my new reality*, indicates that the loneliness of the disease could be alleviated by the interviewees being confirmed by their close friends and relatives, the nurses and their fellow patients. Living a normal life meant being able to rest from the disease, which presupposed a sense of control. The interviewees had adapted to their new reality, which was facilitated by their increased self-efficacy. The interviewees could see the heart pump as a friend, because they could accept the pump as lifesaving. They re-evaluated and expanded their own world to include the pump. They developed a new relationship to the pump: the pump was not alien but rather to a certain extent a part of the lived body, of their own world. Merleau-Ponty (2012) has described this process as an extension of the body and thus the lived body.

The fact that patients treated with MCS undergo a profound process to manage their changed reality as a result of bodily changes has also been explored by Standing and co-workers (2017). Our findings show that patients treated with BiVAD experience a change in self and body image, as also shown in previous research on LVAD patients' experiences (Chapman et al., 2007; Standing et al., 2017). The experience that the parts of the pump can become an extension of the patient's body and that the interface between the body and the MCS changes when the body adapts to the MCS has been described previously (Sandau et al., 2014), which reflects the proposition that the pump was part of the lived body. Our study also suggests that MCS could eventually be partially accepted as a part of the lived body. The fact that our interviewees did not fully see MCS as part of the body may be due to the fact that their BiVAD was a larger pump than other product designs, which gave a significantly larger bodily change than with other MCS equipment.

Our results also highlighted the importance of patients being able to accept the pump treatment, in order to become accustomed to their new existence. This gave them a certain sense of normality in everyday life. Casida and co-workers (2011) also described the importance of accepting MCS in order

to adapt to the changed life situation. The interviewees in our study felt safe when they accepted the MCS treatment. They felt confident about the future despite their dependence on a complicated technology. The significance for wellbeing of such a sense of security was previously described in a study of experiences of heart transplantation (Sadala & Stolf, 2008).

The overall theme of this study, *Navigating from helplessness to feeling strong in a new reality*, shows the importance of self-efficacy in the process that patients undergo for being able to accept MCS treatment in their changed reality. The fact that the interviewees felt that they could independently manage and have control over certain aspects of their daily lives was necessary for their self-efficacy to increase. Previous research has shown a negative correlation between overprotection from significant others, which adversely affected self-efficacy and wellbeing (Joekes, Van Elderen, & Schreurs, 2007). It is therefore of the utmost importance that the support given to patients with MCS enables them to feel a growing self-efficacy through an increased degree of independence.

A sense of managing their wellbeing by controlling their morbidity was found to be a significant factor in the design of The Cardiac Self-Efficacy Scale, CSE. Low CSE was directly correlated with an increased burden of symptoms, impaired physical activity and lower quality of life (Fors, Ulin, Cliffordson, Ekman, & Brink, 2015). Fors and co-workers (2016) has also shown that person- center-care (PCC) given to patients with acute coronary syndrome hasted and promoted their self-efficacy belief, significantly more than usual care. The philosophy of person centeredness highlights the importance of patient´s narrative in order to fully understand and grasp the experience of illness from the patient´s perspective. Mutual understanding and agreement on how to plan and perform the care are also essential in PCC (Ekman et al., 2011). All this findings reinforces the importance of supporting patients with MCS to gain an increased belief in their ability to take control over their changed reality. And with a care designed from the patient's perception of their illness, this support may be improved.

Limitations and strengths

One limitation of the study is that few participants were recruited. The recruitment was limited to Sahlgrenska University Hospital because it is the only centre in Sweden that treats severe biventricular heart failure with BiVAD in form of a para corporeal pump and with blood chamber outside the body. All patients who met the inclusion criteria for the study were included in the current data collection period, which illustrates that younger patients as in this study's age range, and in need of advanced therapy for severe biventricular heart failure constitute are a rare patient group. The eight completed interviews gave a rich source of data and the interviewees had often similar experiences and insights, which indicates that the data collection was sufficiently extensive for a narrative analyse, searching for phenomenal variations (Sandelowski, 1995). One of the interviewee was slightly older than the others and had not onset equally acute. This interviewee' experiences living with MCS distinguish slightly from the others in some matters, which may indicate that factors such as age and a very acute onset affect how patients living MCS handle their changed reality.
Trustworthiness and authencity were strengthened by the choice of method, as the phenomenological-hermeneutical methodology allows the essence of the interviewees' experiences to come to light. The accuracy required in the analysis to both understand and interpret the lived experience in each interviewee's story strengthens the study's credibility (Lindseth & Norberg, 2004), despite the limited selection of patients.

Another strength is that the authors are well-acquainted with caring for patients treated with BiVAD, which has proved valuable in capturing the essence of each interviewee's story. The findings show a consistency that confirms the naïve reading formulated in the initial analysis, which strengthens the authenticity of the study. The result was verified by a comprehensive understanding of the literature which demonstrated coherence that strengthens our findings (Lindseth & Norberg, 2004).

Conclusions and implications

This study shows the importance of self-efficacy belief in the process that younger patients undergo to be able to accept the treatment and their changed reality, while they are living with mechanical circulatory support. Self-efficacy can increase if patients independently manage and have control over certain aspects of daily life activities. The multidisciplinary health-care team who come into contact with patients treated with MCS, and BiVAD in particular, need to be aware of the importance of strengthening patients' self-efficacy belief and of the significance of the lived body. How the abruptly changed life situation affects the patient's entire reality. It is important to have a deep understanding of the process that these patients undergo: from feeling helpless to feeling strong in their new reality. Through in-depth knowledge, the multidisciplinary health-care team can meet and support patients in a better way based on their individual circumstances and their own life-world. A structured person-centred approach in the care of these patients may enhance the patients' confidence in their own ability to grow. Further research is needed to enable the care of patients with MCS to be structured in an empathic and person-centred way.

Relevance to clinical practice

- By strengthening patient self-efficacy, wellbeing can increase. With increased self-efficacy, the changed reality that occurs with MCS treatment is perceived to be manageable and controllable.

- When patients treated with MCS experience control over their situation, they can be transferred to a cardiology outpatient clinic, which for the patients imply a step towards independence and a sense of normality. Further, from a socioeconomic perspective a hospital bed is released for other patients in need of cardiologic specialist care, which is important when care facilities are limited.

Funding

This work was supported with grants by The Local Research and Development Board for Gothenburg and Sodra Bohuslan, Id-Nr: 203771.

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Impact Statement

- Self-efficacy belief plays a significant role for younger patients to be able to accept MCS treatment and to handle a changed reality.

- The significance of the lived body, and how the abruptly changed life situation affects patient's with MCS entire reality.

- With in-depth knowledge, about what MCS treatment means to younger patients with a life-threatening heart failure, the multidisciplinary health-care team can understand and support the patients in a better way.

Tables & Figures

Table 1. *Patient characteristics*

Sex		Age	Days on MCS[†]
Male		35	172
(n =2)		19	81
	Mean	27	126.5
Female		20	137
(n = 6)		22	101
		23	163
		42	168
		28	99
		34	139
	Mean	28	134.5

[†]MCS = mechanical circulatory support

Table 2. *Main theme, themes and subthemes*

Main theme: **Navigating from helplessness to feeling strong in a new reality**		
Feeling homeless in a changed reality	**Finding my own inner resources**	**Coming to terms with my new reality**
A sudden change in life	Facing the disease	Adjusting to a changed life
Lost empowerment	Daring to surrender	Being strengthened by others
An invaded body	Managing to endure it	Seeing the pump as a friend
Being let down by my weak body	Finding my inner strength	Respite from the disease
The loneliness of the disease	Feeling confident	
Life in the slow lane	Regaining control of my own situation	

Fig. 1. *Main theme describing the process of navigating from helplessness to feeling strong in a new reality*